

Ten years of ESPN/ERA-EDTA Registry

By Marjolein Bonthuis, ESPN/ERA-EDTA Registry coordinator

The paediatric registry added to the ERA-EDTA Registry in 1971 was successful for about 25 years. After experiencing major difficulties the Registry stopped providing paediatric data in the 1990s. Between 2000 and 2007 data collection on European children on RRT was restricted to that of the ERA-EDTA Registry, but in 2007 a new paediatric registry, the ESPN/ERA-EDTA Registry, was launched with a progressive increase in countries providing data ever since.

Currently, this Registry is the world's largest population-based registry for paediatric RRT, including individual patient data of nearly 20,000 children from 38 countries. The database includes core data on demography, renal disease, treatment modality and outcomes, as well as a variable subset of anthropometric, clinical, and medication-related parameters. As low patient numbers per country complicate statistically valid and clinical meaningful studies, the Registry enabled us to provide high-quality data in annual statistical reports and 35 scientific papers published in high-ranking medical journals. This way, the Registry con-

tributes to improved evidence-based clinical care for children on RRT.

Health inequalities and practice variation across Europe are an important focus of the Registry. We demonstrated large disparities in access to paediatric RRT and patient survival on RRT, partially explained by country macroeconomics. We also found inequalities in access to optimal nephrology care due to gender and ethnicity. Furthermore, the Registry provided valuable outcome data on rare kidney diseases, such as ARPKD and congenital anomalies of the kidney and the urinary tract. An important part of the Registry's research activities arise from the successful internship programme, which has so far led to 18 researchers from 11 European countries visiting the Registry.

This year the ESPN/ERA-EDTA Registry celebrates its 10th anniversary and we are very proud of all the achievements. We would like to thank everyone for their fruitful collaboration. Our success would not have been possible without your enthusiasm and great efforts!

More information can be found on www.espn-reg.org



The EDITH project



By Vianda Stel, ERA-EDTA Registry epidemiologist and Rianne de Jong, PhD student EDITH project

On 1 January 2017 the EDITH project, which is funded by the 3rd Health Programme of the European Union, started. The acronym stands for "The Effect of Differing Kidney Disease Treatment Modalities and Organ Donation and Transplantation Practices on Health Expenditure and Patient Outcomes". Because there is important variation in practice in the management of end stage kidney disease (ESKD) and access to dialysis and kidney transplantation in Europe, EDITH aims to examine the effect of differing kidney disease treatment modalities and organ donation and transplant practices on health expenditure and patient outcomes. The results of these analyses may have an impact on the treatment choices by patients and doctors and on health care policies.

The EDITH consortium consists of 10 partners from all over Europe together with collaborating stakeholders including renal registries, ERA-EDTA, the European Kidney Patients Federation, European Kidney Health Alliance, and national kidney foundations. The ERA-EDTA Registry participates in a work package that will address the epidemiology and costs of different treatment modalities for ESKD. This includes the assessment of 1) the frequency of the various treatment modalities; 2) factors that influence the choice of those treatment modalities by patients and doctors; and 3) the impact of treatment modality choice on health outcomes as patient survival and quality of life as well as on health care budgets. The analyses on health care budgets will be performed by the Italian National Transplant Center.



Other work packages will set up a European Living Donor Registry and a European Kidney Transplant Registry for the follow-up of living donors and transplant recipients.

See also www.edith-project.eu.

The EURODOPPS project

The EURODOPPS project, which is a collaborative venture between DOPPS and the ERA-EDTA Registry is proceeding well. Since the beginning of 2017, two research papers based on the EURODOPPS data have been finalized. First, a paper by Sophie Liabeuf et al. on the relationship between attainment of guideline targets and a country's healthcare expenditure and nephrologist workforce, has been pub-

lished in Nephrology Dialysis Transplantation. Second, a paper on geographical variations in blood pressure level and seasonality by Flore Duranton et al. has been submitted for publication. There are currently five more research projects nearing completion. In the DOPPS Symposium on Monday 5 June (15:15-16:45 p.m.) Dr. Ayesha Sajjad will provide an update on these on-going projects.



Leading European Nephrology

ERA-EDTA President
Andrzej Więcek
Katowice, Poland

Registry Committee

Ziad Massy (Chair)
Paris, France

Fergus Caskey
Bristol, United Kingdom

Cécile Couchoud
Saint Denis La Plaine, France

Marie Evans
Stockholm, Sweden

Patrik Finne
Helsinki, Finland

Jaap Groothoff
Amsterdam, Netherlands

Jérôme Harambat
Bordeaux, France

James Heaf
Copenhagen, Denmark

Faïçal Jarraya
Sfax, Tunisia

Maurizio Nordio
Padua, Italy

Ivan Rychlik
Prague, Czech Republic

Staff

Kitty Jager
Managing Director /
Epidemiologist

Ronald Cornet
Senior IT Specialist

Vianda Stel
Epidemiologist

Marlies Noordzij
Epidemiologist

Anneke Kramer
Medical Information Scientist

Maria Pippias
MD / PhD Student

Arno Weerstra
Data Manager

Gita Guggenheim
Secretary

Educational activities beyond European borders

by Marlies Noordzij, ERA-EDTA Registry epidemiologist

SLANH / ERA-EDTA Registries Fellowships

The 6-month SLANH / ERA-EDTA Registries fellowships were designed to enable young Latin American nephrologists to train in clinical epidemiology and to obtain registry skills at the ERA-EDTA Registry in Amsterdam. Between October 2015 and April 2016 Rosario Luxardo from Argentina visited the Registry. She worked on a project comparing the epidemiology of RRT in Europe and Latin America and made a start with a project on trends over time in the prevalence of comorbidities in European RRT patients. This project was taken over by Laura Ceretta from Uruguay who visited the Registry from September 2016 to March 2017. Now that Rosario and Laura have successfully finalized their fellowships, the knowledge and skills they gained will help them to improve the quality of the data collection in their national renal registries and the Latin American Dialysis and Renal Transplantation Registry (RLADTR).

Pre-AFRAN congress course

Since 2004 the ERA-EDTA Registry organizes Introductory Courses on Epidemiology throughout Europe of which the 30th edition took place last April in Cyprus. In addition to the regular courses, sometimes special editions are organized outside Europe. A recent example of such a special course is the one-day programme "An introduction to Epidemiology" that was organized as pre-AFRAN congress course in Yaounde, Cameroon (14 March 2017). Ziad Massy, Kitty Jager and Maria Pippias taught 70 participants from all over the African continent the basic principles of epidemiology. The course was very much appreciated by the participants and we hope that more African nephrologists can be reached with future initiatives.



ERA-EDTA Registry activities during the 54th ERA-EDTA Congress in Madrid, Spain

CME 5: Cross-talk in Renal Epidemiology Saturday June 3, 08:30 - 11:45 a.m., Hall 10.B.

- Sample size calculations
- The contribution of cross sectional studies to nephrology
- A joint model to describe CKD progression and mortality in CKD patients: a practical guide
- Restricted mean survival time: an alternative to the hazard ratio
- The importance of considering competing treatment affecting prognosis in RCTs
- Marginal structural models in clinical research: when and how to use them
- Can we use routine primary care data to estimate how many people with CKD there are? An example using UK primary care data

- Characteristics and outcomes of patients with systemic sclerosis (scleroderma) requiring RRT
- Modification of the "long gap" phenomenon by hemodialysis treatment time
- Gender differences in advanced CKD
- Recovery of renal function in paediatric RRT

Posters

Posters presenting studies performed within the national and regional renal registries can be found in the Poster Area of the IFEMA Feria de Madrid (North Congress Center).

ERA-EDTA Registry booth

Please visit our booth in the exhibition hall to meet the Registry staff and for questions on educational activities, research collaborations or other registry matters.

Symposium 4: ERA-EDTA Registry Symposium

Sunday June 4, 8:00 - 9.30 a.m., Hall N 101-102.

- Ten year trends of renal transplantation in recipients aged 75 years and older

